Brief Comprehensive Quality of Life Assessment After Stroke
The Assessment of Quality of Life Instrument in the North East Melbourne Stroke Incidence Study (NEMESIS)

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Background and Purpose—Generic utility health-related quality of life instruments are useful in assessing stroke outcome because they facilitate a broader description of the disease and outcomes, allow comparisons between diseases, and can be used in cost-benefit analysis. The aim of this study was to validate the Assessment of Quality of Life (AQoL) instrument in a stroke population.

Methods—Ninety-three patients recruited from the community-based North East Melbourne Stroke Incidence Study between July 13, 1996, and April 30, 1997, were interviewed 3 months after stroke. Validity of the AQoL was assessed by examining associations between the AQoL and comparator instruments: the Medical Outcomes Short-Form Health Survey (SF-36); London Handicap Scale; Barthel Index; National Institutes of Health Stroke Scale; and Irritability, Depression, Anxiety scale. Sensitivity of the AQoL was assessed by comparing AQoL scores from groups of patients categorized by severity of impairment and disability and with total anterior circulation syndrome (TACS) versus non-TACS. Predictive validity was assessed by examining the association between 3-month AQoL scores and outcomes of death or institutionalization 12 months after stroke.

Results—Overall AQoL utility scores and individual dimension scores were most highly correlated with relevant scales on the comparator instruments. AQoL scores clearly differentiated between patients in categories of severity of impairment and disability and between patients with TACS and non-TACS. AQoL scores at 3 months after stroke predicted death and institutionalization at 12 months.

Conclusions—The AQoL demonstrated strong psychometric properties and appears to be a valid and sensitive measure of health-related QoL after stroke. (Stroke. 2002;33:2888-2894.)

Key Words: cerebrovascular disorders ■ health status ■ outcome assessment ■ quality of life

Health-related quality of life (HRQoL) is an important index of outcome after stroke and is likely to be more relevant to the patient than impairment or disability.1–3 Measurement of HRQoL may be useful in natural history studies, in assessing the effectiveness of acute interventions, and in the evaluation of rehabilitation and community support programs. From a societal perspective, it is also important to measure the efficiency of interventions, including health gains per monetary value expended. Although there is debate about the relative merits of generic versus stroke-specific HRQoL measures,2,3 generic utility HRQoL instruments can directly measure health status, allow comparison across diseases, and facilitate economic evaluation.

The Assessment of Quality of Life (AQoL) instrument4,5 was designed (1) to ensure coverage of the full universe of HRQoL, (2) to meet standard psychometric requirements for reliable and valid measurement, (3) to be sensitive to a wide range of health states from very good to extremely poor health, and (4) to deliver psychometrically sound scores on the different dimensions of HRQoL. The AQoL has been successfully used in nonstroke populations.6–10 Other generic instruments have been used to collect HRQoL data in stroke survivors. These include the Medical Outcomes Short-Form Health Survey (SF-36),11 and the Euroqol.12 Both have been criticized for a lack of sensitivity.2 Similar to the Euroqol, the AQoL yields both a descriptive profile and a single value that quantifies overall HRQoL. The Euroqol is simple and slightly quicker to complete than the AQoL but appears to have poorer coverage of stroke-relevant HRQoL. The SF-36 takes longer to complete than the AQoL. Scores are provided from 8 subscales (or 2 summary subscales). The use of multiple subscales may be viewed as advantageous because of the diversity in the recovery process from stroke; however, it may also make the interpretation of overall outcome difficult because gains in 1 domain can be offset by losses in other domains. The AQoL appears to have advantages...
over existing generic measures of HRQoL and health status in that it offers brief assessment, better coverage of stroke-specific domains (eg, communication and vision), and 1 overall score facilitating analysis and can be used in economic analysis. However, the validity of the AQoL as a measure of HRQoL in stroke has not been established. The aim of this study was to validate the AQoL as a measure of HRQoL in a population of stroke survivors.

Methods

The North East Melbourne Stroke Incidence Study

Stroke survivors were recruited from the North East Melbourne Stroke Incidence Study (NEMESIS), a community-based study of the incidence, risk factors, and outcomes of stroke in the northeastern suburbs of Melbourne, Australia. The methods have previously been described in detail. Briefly, NEMESIS was conducted in an 8-postal code region containing a population of ~133,816 in northeastern Melbourne between May 1, 1996, and April 30, 1997. The methodology used to obtain stroke cases was based on the recommendations for the conduct of “ideal” stroke incidence studies. All potential cases of stroke were reviewed by a panel of at least 2 neurologists and 1 epidemiologist before inclusion in the study. Cases meeting the World Health Organization (WHO) definition of stroke were registered. Pathological subtypes of stroke (cerebral infarction [CI], intracerebral hemorrhage [ICH], and subarachnoid hemorrhage [SAH]) was determined on the basis of neuroimaging, lumbar puncture, or autopsy findings as described previously. Patients who had neither neuroimaging nor autopsy were classified as undetermined. Patients were further categorized by an expert panel blinded to brain imaging findings that used the NEMESIS study.

Follow-Up

Patients were administered the AQoL and comparator instruments by trained research nurses via face-to-face interview 3 months after stroke. If a patient was unable to complete the interview because of dementia or aphasia, a face-to-face proxy interview was sought from the best available informant, usually the next of kin or, if necessary, a professional caregiver.

Subjects

For the purposes of the present study, all patients who had a first-ever-in-a-lifetime or recurrent stroke (CI, ICH, or undetermined but not SAH) between July 13, 1996, and April 30, 1997, were eligible for inclusion. Two hundred sixty-one patients had a stroke (CI, ICH, or undetermined) in this period. At 3 months after stroke, 72 (28%) were deceased. Thirty-three patients (13%) were notified to the NEMESIS study >3 months after stroke, and 63 (24%) refused to take part. Therefore, 93 patients (60% of those approached, 49% of those alive at 3 months) were enrolled in the study. The mean age was 72 years (range, 28 to 89 years), 45% were male, and 70% were born in Australia; for 83%, this was a first-ever-in-a-lifetime stroke. Of the total patients, 10% had total anterior circulation infarction, 37% had partial anterior circulation infarction, 19% had posterior circulation infarction, 26% had lacunar infarction, and 6% had ICH; in 2 patients, stroke type was undetermined. Patients included in this study did not differ significantly from those who refused to take part or were notified late to the NEMESIS study in terms of age, sex, stroke subtype, or prestroke disability. Those not included were significantly more likely to have been born outside Australia (P = 0.05) and to have been admitted to a private hospital (P = 0.02).

Instruments

The AQoL instrument is a generic HRQoL utility instrument that includes 5 dimensions of HRQoL: independent living, social relationships, physical senses, psychological well-being, and illness (reproduced in full in the Appendix). Scores from the first 4 dimensions only are used to calculate an overall utility score. Each individual scale is weighted to extend between 0.0 (death) and 1.0 (full health). However, the overall utility score range is from −0.04 (worst possible HRQoL state) to 0.00 (death-equivalent HRQoL state) to 1.00 (full HRQoL). The utilities were derived using time tradeoff methodology in a sample of the general population. The AQoL was designed to be administered by self-completion, through face-to-face interview, or via proxy. It takes ~5 minutes to complete and has been well validated in the general population.

The SF-36 is a widely used and validated generic HRQoL instrument. It comprises 8 subscales: physical functioning, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health. Each of the subscales is scored separately using item weighting and additive scaling. Summed data are transformed onto a 0- to 100-point scale. The 8 subscales can be combined into 2 summary health status measures, physical and mental health. The acute (1-week time frame) version of the SF-36 was used.

Impairment was measured with the Neurological Impairment Score (NIHSS) (range, 0 to 42). Patients were categorized into prespecified groups by severity of impairment with 5-point intervals. Categorization into 5-point intervals has been used in previous studies and represents a clinically relevant score threshold. Because of the small number of patients with very high impairment scores in our sample, we collapsed the patients scoring >10 into 1 category, ie, 0 to 5, 6 to 10, and >10. Disability was assessed with the Barthel Index. Patients were scored according to current actual performance of activities of daily living. Severity of disability was determined by stratifying patients into prespecified categories: very severely (Barthel 0 to 4), severely (5 to 9), moderately (10 to 14), or mildly (15 to 19) disabled or nondisabled (20 to 25).

Handicap was assessed with the London Handicap Scale (LHS). This provides a descriptive profile of disadvantages experienced in the domains of mobility, physical independence, occupation, orientation, social functioning, and economic self-sufficiency. A weighted total handicap score is produced, with scores ranging from 0 (maximum disadvantage) to 100 (no disadvantage).

Statistical Analysis

The construct validity of the AQoL was assessed by examining the relationships between the AQoL (individual dimensions and total utility score) and the NHISS, Barthel Index, LHS, SF-36 subscales, and the depression and anxiety subscales of the IDA at 3 months after stroke using Spearman’s rank correlation coefficient (R). For a sample size of 93 and the null hypothesis R = 0, the critical values are P = 0.05, R ≈ 0.204; P = 0.01, R ≈ 0.267; and P = 0.001, R ≥ 0.338. We hypothesized that the magnitude of correlation would be highest between scales measuring similar constructs (providing evidence of convergent validity) and the weakest correlations would be between scales measuring conceptually unrelated constructs (discriminant validity). For example, we expected that the independent living dimension of the AQoL would be more highly correlated with the Barthel Index than with measures of mental health and, conversely, the psychological well-being dimension to be more highly correlated with the IDA subscales than with the Barthel Index.

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We compared the AQoL with instruments that measure different levels of outcome according to the WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH). These questionnaires were chosen to enable comparison between AQoL scores and scores from established instruments that measure different levels of outcome according to the WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH).27
AQoL. The RE is a commonly used statistic that allows a simple
calculation of the AQoL utility scores for each instrument and compared with the RE of the
AQoL score according to severity of disability 3
Figure 1.

Relative efficiencies (RE), the ratio of the squares of
the NIHSS, Barthel Index, LHS, and SF-36; 88 were assessed with the NIHSS; and 79
were assessed with the IDA.

comparison of the relative abilities of different instruments to detect
differences between groups.29,30 The RE was applied to a known-
groups comparison in which patients categorized as TACS would be
expected to have lower health status than patients with other
subtypes of stroke at 3 months after stroke because they have
significantly greater disability, handicap, and levels of dependency.17,31,32 Patients with definite ICH were excluded from the TACS/
non-TACS analysis because these patients may be drowsy initially
(and classified as TACS) but make a good recovery by 3 months.

The predictive validity of the AQoL was assessed by testing the
hypothesis that the AQoL utility score at 3 months after stroke would
predict the outcomes of death, institutionalization, or both 12 months
after stroke. Logistic regression was used to produce models describing
the relationship between 3-month AQoL scores and these outcomes.

Discrimination of the predictive models was assessed by calculating the
area under a receiver-operating characteristic curve (AUC) of sensitivity
versus 1 minus specificity. An AUC of 1 implies perfect prediction,
whereas an AUC of 0.5 implies the that predictions of that model are no
better than chance. Multiple logistic regression was performed to
determine whether AQoL score at 3 months remained an independent
predictor of death and institutionalization at 12 months when adjusted
for age, sex, and impairment score.

Analyses were performed with the SPSS package (version 10.0 for
Windows).

Results

All 93 patients completed the AQoL. Fifteen subjects (16%) were
assessed by means of a proxy response. The mean AQoL utility
score was 0.404, the median was 0.365, and the SD was 0.333. The
data were not significantly skewed, and scores were distributed
evenly throughout the available range. Two patients (2%) scored
0.04 (lowest possible score), and only 1 patient (1%) scored 1.0
(highest possible score), demonstrating no substantial floor or
ceiling effects. Ninety-two patients were assessed with the Barthel
Index, LHS, and SF-36; 88 were assessed with the NIHSS; and 79
were assessed with the IDA.

### TABLE 1. Association Between the AQoL and Other Health Status Measures in Patients 3 Months After Stroke (Spearman’s rank correlation)

| Dimensions of the AQoL | SF-36 | | | | | |
|------------------------|------|---|---|---|---|
| Illness* | 0.30† | 0.77§ | 0.37§ | 0.28† | 0.26† | 0.69§ |
| Living | 0.24† | 0.20 | 0.26† | 0.19 | 0.19 | 0.27† |
| Relationships | 0.21† | 0.06 | 0.16 | 0.04 | 0.01§ | 0.20 |
| Physical | 0.31† | 0.27§ | 0.25† | 0.21† | 0.39§ | 0.36§ |
| Senses | 0.17 | 0.39§ | 0.41§ | 0.26† | 0.37§ | 0.47§ |
| Psychological | 0.20 | 0.44§ | 0.48§ | 0.31† | 0.36§ | 0.54§ |
| Wellbeing | 0.09 | 0.00 | 0.21† | 0.37§ | 0.18 | 0.15 |
| AQL Total | 0.04 | 0.40§ | 0.50§ | 0.31† | 0.41§ | 0.51§ |
| Score*Illness* | 0.35§ | 0.44§ | 0.22† | 0.07 | 0.38§ | 0.44§ |
| Barthel Index (disability) | 0.06 | 0.19 | 0.44§ | 0.39§ | 0.32† | 0.36§ |
| London Handicap Scale | 0.30† | 0.82§ | 0.56§ | 0.52§ | 0.32† | 0.83§ |
| NIHSS (impairment) | 0.25† | 0.85§ | 0.44§ | 0.45§ | 0.16 | 0.77§ |
| Anxiety | 0.15 | 0.51§ | 0.49§ | 0.31† | 0.47§ | 0.60§ |
| Depression | -0.15 | -0.41§ | -0.44§ | -0.12 | -0.53§ | -0.53§ |

*Scores from the Illness dimension are not included in the calculation of the AQoL utility score.
†P<0.05, ‡P<0.01, §P<0.001 for the hypothesis

*One patient refused a Barthel Index assessment.

Figure 1. AQoL score according to severity of disability 3 months after stroke (n=92).
The association between the AQoL and its individual dimensions and the other instruments is shown in Table 1. The magnitude of the correlations was greatest between scales with the most similar construct. The independent living dimension of the AQoL correlated most strongly with the Barthel Index (R=0.85), followed by the LHS (R=0.82), NIHSS (R=−0.74), and SF-36 physical functioning subscale (R=0.77). The social relationships dimension was most highly correlated with the LHS (R=0.56), anxiety (R=−0.49), and SF-36 social functioning (R=0.48) and mental health (R=0.50) subscales. The physical senses dimension correlated most strongly with the LHS (R=0.52), Barthel Index (R=0.45), and NIHSS (R=−0.40). The highest correlations for the psychological well-being dimension were with the depression (R=−0.53) and anxiety (R=−0.47) subscales and the SF-36 bodily pain (R=0.61) and mental health (R=0.41) subscales. The total AQoL score was most highly associated with the LHS (R=0.83) and Barthel Index (R=0.77).

The relationships between mean AQoL score and categories of disability (Figure 1) and impairment were in the expected direction. Highest HRQoL was observed when disability and impairment were least. The differences in total AQoL scores across categories of disability and impairment were significant (P<0.001, ANOVA).

The total AQoL and independent living dimension, SF-36 physical function subscale, LHS, Barthel Index, and NIHSS discriminated significantly between the health status of TACS and non-TACS patients in both parametric (t test) and nonparametric (permutations test) analyses (Table 2).

The AQoL utility score (RE referenced to 1.0) discriminated between TACS and non-TACS patients more efficiently than the SF-36 (RE, 0.01 to 0.54), LHS (RE, 0.45), Barthel Index (RE, 0.50), IDA (RE, 0.02 to 0.10), and NIHSS (RE, 0.47). Only the independent living subscale of the AQoL discriminated between these groups of patients with more efficiency than the total AQoL score (RE, 1.84).

In logistic regression models, the AQoL 3-month score was a significant predictor of the outcomes of death (13 cases), institutionalization (7 cases), or both 12 months after stroke. The follow-
We have provided evidence that the AQoL is a valid instrument for assessing HRQoL after stroke. The strongest associations of AQoL and its dimensions with other measures were observed between scales measuring similar constructs, and the weakest relationships were between conceptually unrelated scales, indicating convergent and discriminant validity. The independent living dimension, as expected, correlated best with measures of physical impairment, handicap, and physical functioning. The social relationships dimension correlated most highly with measures of disability, social functioning, and mood impairment, suggesting that both physical and psychological functioning is important for satisfying relationships. The physical senses dimension correlated best with disability and handicap measures. Low correlations between this dimension and SF-36 scales are expected because the items covered (seeing, hearing, communication) are not specifically addressed by the SF-36. The psychological well-being dimension was correlated most highly with other measures of psychological function. The psychological well-being incorporates pain assessment, which explains the high correlation with the SF-36 bodily pain scale.

Total AQoL utility scores were more strongly correlated with scores from the LHS (handicap) than with the Barthel Index (disability) and NIHSS (impairment), and this, together with the moderate correlation between the AQoL and most SF-36 subscales, suggests strong criterion validity. The highest correlation was with the SF-36. The psychological well-being incorporates pain assessment, which explains the high correlation with the SF-36 bodily pain scale.

Figure 2. Death and institutionalization 12 months after stroke according to AQoL utility score 3 months after stroke.

The AQoL was sensitive in discriminating differences in health status between patients with varying severity of stroke, as defined by disability and impairment scores. The utilities observed for severe and mild stroke are similar to those reported elsewhere. The SF-36 is used to describe the patient’s health status largely in terms of the impact of health on activities, although perception of general health status and mood are also assessed. Dimension scores for the SF-36 are computed with a non-preference-weighted additive model in which the scores representing health status are quantified on a 0-to-100-point rating scale. Given these differences between instruments, the correlations are of the magnitude expected.

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extremity function and cognition, as included in stroke-specific HRQoL instruments,6,36,37 the AQoL performs well. Despite its brevity, it captures much of the variance of the handicap, disability, and impairment instruments and returns information on broader aspects of HRQoL. The performance of the AQoL is most likely due to the relevance of its domains to stroke survivors (self-care, household tasks, mobility, relationships, social isolation, family role, seeing, hearing, communication, sleep, anxiety and depression, and pain). The questionnaire is easy to use, taking 5 minutes to administer to most patients. It can be used in a variety of settings because it was designed for self-completion or use at interview, and it appears suitable for proxy assessments.

Recently, a stroke-specific QOL scale (12 domains, 78 items)36 and a stroke impact scale (8 domains, 64 items) have been developed.37 These have the advantage of returning substantial detail on stroke-specific outcomes, but their length, lack of a single outcome score, and inability to be used in nonstroke comparison groups may make them unsuitable for use in some studies. Further validation of the AQoL using stroke-specific HRQoL scales would be useful.

The AQoL can be recommended for use in cross-sectional studies of outcome after stroke. Further evaluation is required to replicate these findings in other stroke populations, to explore the major stroke subtypes: initial findings from the North East Melbourne Stroke Incidence Study (NEMESIS). Stroke. 2001;32:1732–1738.

Appendix

THE Australian Quality of Life (AQOL) INSTRUMENT

INSTRUCTIONS:
Please tick the alternative that best describes you during the last week.

ILLNESS

1. Concerning my use of prescribed medicines:
   - I do not or rarely use any medicines at all.
   - I use one or two medicinal drugs regularly.
   - I need to use three or four medicinal drugs regularly.
   - I use five or more medicinal drugs regularly.

2. To what extent do I rely on medicines or a medical aid? (NOT glasses or a hearing aid.) (For example: walking frame, wheelchair, prosthesis etc.)
   - I do not use any medicines and/or medical aids.
   - I occasionally use medicines and/or medical aids.
   - I regularly use medicines and/or medical aids.
   - I have to constantly take medicines or use a medical aid.

3. Do I need regular medical treatment from a doctor or other health professional?
   - I do not need regular medical treatment.
   - Although I have some regular medical treatment, I am not dependent on this.
   - I am dependent on having regular medical treatment.
   - My life is dependent upon regular medical treatment.

INDEPENDENT LIVING

4. Do I need any help looking after myself?
   - I need no help at all.
   - Occasionally I need some help with personal care tasks.
   - I need help with the more difficult personal care tasks.
   - I need daily help with most or all personal care tasks.

5. When doing household tasks: (For example, preparing food, gardening, using the video recorder, radio, telephone or washing the car)
   - I need no help at all.
   - Occasionally I need some help with household tasks.
   - I need help with the more difficult household tasks.
   - I need daily help with most or all household tasks.

6. Thinking about how easily I can get around my home and community:
   - I get around my home and community by myself without any difficulty.
   - I find it difficult to get around my home and community by myself.
   - I cannot get around the community by myself, but I can get around my home with some difficulty.
   - I cannot get around either the community or my home by myself.

SOCIAL RELATIONSHIPS

7. Because of my health, my relationships (For example: with my friends, partner or parents) generally:
   - Are very close and warm.
   - Are sometimes close and warm.
   - Are seldom close and warm.
   - I have no close and warm relationships.

8. Thinking about my relationship with other people:
   - I have plenty of friends, and am never lonely.
   - Although I have friends, I am occasionally lonely.
   - I have some friends, but am often lonely for company.
   - I am socially isolated and feel lonely.

9. Thinking about my health and my relationship with my family:
   - My role in the family is unaffected by my health.
   - There are some parts of my family role I cannot carry out.
   - There are many parts of my family role I cannot carry out.
   - I cannot carry out any part of my family role.

PHYSICAL SENSES

10. Thinking about my vision, including when using my glasses or contact lenses if needed:
   - I see normally.
   - I have some difficulty focusing on things, or I do not see them sharply.
   - For example: small print, a newspaper, or seeing objects in the distance.
   - I have a lot of difficulty seeing things. My vision is blurred.
   - For example: I can see just enough to get by with.
   - I only see general shapes, or am blind.
   - For example: I need a guide to move around.

11. Thinking about my hearing, including using my hearing aid if needed:
   - I hear normally.
   - I have some difficulty hearing or I do not hear clearly.
   - For example: I ask people to speak up, or turn up the TV or radio volume.
   - I have difficulty hearing things clearly.
   - For example: Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.
   - I hear very little indeed.
   - For example: I cannot fully understand loud voices speaking directly to me.

12. When I communicate with others: (For example: by talking, listening, writing or signing)
   - I have no trouble speaking to them or understanding what they are saying.
   - I have some difficulty being understood by people who do not know me.
   - I have some trouble understanding what others are saying to me.
   - I am only understood by people who know me well.
   - I have great trouble understanding what others are saying to me.
   - I cannot adequately communicate with others.

PSYCHOLOGICAL WELL-BEING

13. If I think about how I sleep:
   - I am able to sleep without difficulty most of the time.
   - My sleep is interrupted some of the time, but I am usually able to go back to sleep without difficulty.
   - My sleep is interrupted most nights, but I am usually able to go back to sleep without difficulty.
   - I sleep in short bursts only, I am awake most of the night.

14. Thinking about how I generally feel:
   - I do not feel anxious, worried or depressed.
   - I am slightly anxious, worried or depressed.
   - I feel moderately anxious, worried or depressed.
   - I am extremely anxious, worried or depressed.

15. How much pain or discomfort do I experience?
   - None at all.
   - I have moderate pain.
   - I suffer from severe pain.
   - I suffer unbearable pain.
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